



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	27	Jan	2020		28	Jan	2021

Section A Reference and administration details

Charity name

Other names charity is known by

Registered charity number (if any)

Charity's principal address

TRACCS, Paediatric and Adolescent Department,	
University College Hospital London, 6th floor central,	
250 Euston road, London	
Postcode	NW1 2PG

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Mrs Karen Anna Gregorowski	Chair		BACME AGM
2	Mrs Christine Mary Oliver	Deputy Chair & Treasurer		BACME AGM
3	Ms Deborah Karen Roberts	Board Secretary & Research executive		BACME AGM
4	Dr Victoria Louise McKeever	Information and communication executive		BACME AGM
5	Mrs Kirsty Northcott	Training & Education executive		BACME AGM
6	Mrs Ceridwen Rutter	Patient & Public Involvement executive		BACME AGM
7	Mrs Beverly Knopps	Non-executive Trustee		BACME AGM
8	Mrs Charlotte Joanna Adler	Non-executive Trustee		BACME AGM
9	Miss Rhonda Valerie Knight	Non-executive Trustee (PPI)		BACME AGM
10	Mr Les Parry	Non-executive Trustee (PPI)		BACME AGM
11	Dr Jayne Woodcock	Non-executive Trustee		BACME AGM
12	Mrs Michelle Selby	Non-executive Trustee		BACME AGM
13	Dr Peter Gladwell	Non-executive Trustee		BACME AGM
14	Mrs Deborah Gale	Non-executive Trustee		Did not stand for re-election at Jan 28 th 2021 AGM

15	Mrs Deborah Gardner	Non-executive Trustee	Appointed by formal election at AGM on 28 th Jan 2021
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Section B Structure, governance and management

Description of the charity's trusts

Type of governing document <small>(eg. trust deed, constitution)</small>	BACME Constitution
How the charity is constituted <small>(eg. trust, association, company)</small>	BACME is an association
Trustee selection methods <small>(eg. appointed by, elected by)</small>	<p>Trustees are appointed by an election process conducted at AGM and in accordance with the BACME constitution.</p> <p>The following conditions are cited at section 12.2 of the BACME constitution;</p> <ul style="list-style-type: none"> • Charity trustees must be a member of a professional body relevant to their professional role and deliver or support clinical care to people with CFS/ME. In the case of patient representatives, Trustees must have direct personal experience of the condition, either as a patient or carer and be affiliated with a chronic fatigue syndrome (CFS/ME) service delivering care in line with BACME objects. • Charity trustees agree to uphold and support the BACME constitution. • Charity Trustees must hold current BACME membership and have been a BACME member for a minimum of 6 months prior to becoming a trustee

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

The embedded Trustee training presentation below has been used to prepare Trustees for CIO status which was awarded by the Charity commission on the 8th January 2021

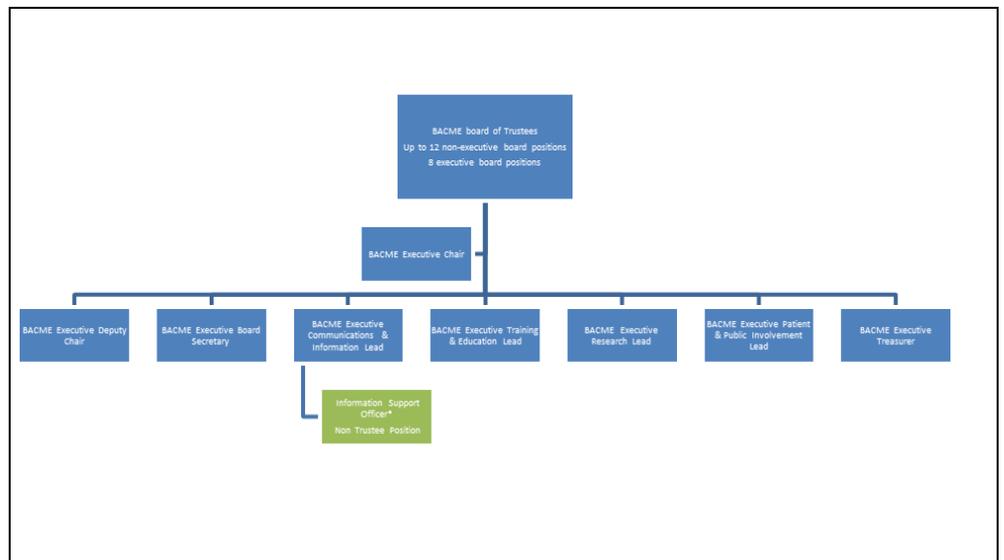


Introduction to the role of Trustee-Jan 2021

Further in depth trustee training is planned for the forthcoming year

[BACME conflict of interest policy](#)

BACME organisational structure



Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

The following is an extract from BACME constitution section 3:

The relief of sickness for the public benefit by:

- 3.1 Championing clinically effective practice in treating CFS/ME and other primary fatigue conditions
- 3.2 Disseminating of recent evidence and practice to clinical practitioners
- 3.3 Providing education and training for members respecting up-to-date evidence and best shared practice
- 3.4 Advocating for equity of access and excellence in the provision of services
- 3.5 Facilitating networking amongst clinicians, researchers and patients
- 3.6 Advocating for and promoting relevant research and to publish all useful results arising from any research supported

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

BACME carries out its purposes for the public benefit and the relief of sickness through board meetings, educational webinars, maintaining an up to date website, an annual conference, regular newsletters and collaboration with relevant organisations and patient groups.

BACME membership is open to clinical professionals who are actively involved in providing or supporting a CFS/ME service which provides health care to members of the public who have CFS/ME. BACME training events are primarily tailored for its membership. Conference is open to non-members who are professionals working in the field of CFS/ME. BACME provides a clear public benefit ; the relief of sickness by supporting BACME members to deliver up to date, clinically effective treatment in the field of CFS/ME which reduces sickness by improving outcomes, quality of life and experiences for this patient group.

All trustees have signed the statutory declaration regarding guidance issued by the charity commission on public benefit.

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

The attached presentation was delivered at the AGM on the 28th Jan 2021 and includes a summary of the main achievements of BACME during the year

[AGM presentation](#)

Summary of BACME key achievements and performance relating to BACME objectives in the relief of sickness for the public benefit.

1. Championing clinically effective practice

- Post viral fatigue management guide
- BACME position paper- Dysregulation model
- Collated response to draft NICE ME/CFS guideline

2. Dissemination of recent evidence & practice

- Peer Supervision & topic based webinars
- Dissemination of BACME position paper
- Newsletters & Communications with BACME members
- Dissemination of NICE response to members

3. Provision of education & training

- Peer review & topic based webinars
- Newsletters & communications

4. Advocating for equity & excellence

- All BACME activities
- Becoming a Charitable Incorporated Organisation

5. Facilitating networking

- Webinars
- BACME Executive members attending CMRC conference

6. BACME Chair is a CMRC Associate Board member

7. Advocate, promote and disseminate research

- Newsletters & Communications

Chairs report

It is with great pleasure and pride that I am writing this report as BACME Chair to share what we have collectively achieved and the ways we met our overall objective of the relief of sickness during 2020, an unprecedented and phenomenal year on our planet. The BACME Board works as a remarkable team, each Executive member and Trustee bringing unique skills and strengths to the table while recognising and respecting each other's talents and showing kindness to each other. It is not surprising to me that the work of BACME continued and transformed during this time of global uncertainty and BACME met all key objectives. Our first aim of relieving sickness by championing clinically effective practice in treating CFS/ME and other primary fatigue conditions has been met as follows: in response to the pandemic, BACME, in collaboration with the York fatigue service, published a post viral fatigue guideline intended for use by all affected by post viral fatigue and professionals working in this field, many thanks to Dr Vikki McKeever, Executive Communication and Information Lead, for facilitating this work; the BACME Board held a number of extraordinary meetings to agree a position paper on key evidence based treatments for CFS/ME, thank you for to all Executive Team members and trustees involved in this process; BACME delivered webinars on significant and relevant topics including Virtual working with individual patients and groups during the Covid

period and on Dysregulation theory and translating this into practice, many thanks to Kirsty Northcott, Executive Training and Education Lead for ensuring a continued programme of relevant and timely Education and peer supervision webinars; in December BACME submitted an extensive, collaborative response regarding the draft NICE ME/CFS guideline, many thanks to the NICE response team, thank you again to Vikki, Deb Roberts BACME Executive Board Secretary and Research lead, Ceri Rutter Patient and Public Involvement Lead working with Rhonda Knight and Les Parry, to Trustee Dr Pete Gladwell, and all who gave their time to assist with the completion of this response. We received many thanks from members for doing this.

Dissemination of recent evidence and practice occurred through regular peer supervision, topic-based education webinars, the dissemination of a position paper, regular newsletters and key messages sent to members during the year. Vikki works extremely hard and seemingly tirelessly to ensure timely and pertinent communication with members while Deb working with Rhonda and Emily Tims ensure newsletters are high quality, evidence based and sent out at regular intervals. Collating and disseminating the position paper, a BACME Board team effort, ensured being up to date with most recent relevant research as did the collation of a high-quality NICE response representative of members and services. Thank you to many BACME members for providing material for this response.

We continued to advocate for equity of access and excellence in the provision of CFS/ME services in 2020. Becoming a Charitable Incorporated Organisation on January the 8th 2021 will ensure we can work with services at a more strategic level in more and effective ways. While this is a team achievement, it would not have happened without the determination and attention to detail provided by BACME Executive Deputy Chair and Finance Lead, Christine Oliver. Thank you very much for continuing to keep focussed on this goal when other Executive members were working on the position paper, NICE response, and webinars. Christine has an extraordinary capacity for multitasking and seemingly boundless energy, a very good combination for excellent outcomes.

Regular peer supervision webinars provided the vehicle for on-going facilitation of networking amongst clinicians. Attendance of five BACME Board members at the CMRC conference in Bristol in March 2020, enabled effective and meaningful facilitation between clinicians, researchers, and patients. As BACME Chair, I continue to be part of the CMRC, allowing for collaboration between organisations. Executive Research Lead, Deb Roberts ensured that we continue to advocate for and publish all useful results arising from research supported by BACME, through publication in newsletters.

Throughout this past year we have been lucky to have three patient / carer representatives involved in each outcome achieved by BACME Board, many thanks to Ceri Rutter, Rhonda Knight and Les Parry for the experience, insight, and wisdom you bring to BACME Board, this is most valuable.

Many thanks too to the quieter members of BACME Board who have worked in the background picking up essential tasks whenever required, Charlie Adler, Bev Knopps, Jayne Woodcock and Michelle Selby. We said goodbye and special thanks to Trustee Sue Luscombe for many years of contribution to BACME Board and CFS/ME Dietetics when she retired from the Board in the Autumn. A big thank you too to Harpinder Aujla, information support officer working with Vikki. Pinda has been instrumental in looking after membership information and the BACME website, working with Vikki and Christine.

Overall, this has been an excellent year for BACME with an increase in

Section D

Achievements and performance

membership, participation, and engagement. BACME has been approached by a number of organisations in 2020 to explore increased collaboration. We look forward to another productive year in 2021. Next steps include a conference in May, updating and producing new guidance in 2021 to further support members, ensuring an on-going programme of webinars and similar educational events, forming young people's and severely affected advisory groups and another year of what we hope will be increased membership, paying particular attention to less represented professional groupings while keeping patients, carers, and representatives at the heart of all we do.

BACME Chair Anna Gregorowski

Section E

Financial review

Brief statement of the charity's policy on reserves

The charity aims to maintain reserves for the following;

- Educational grant reserve £5000
- Contingency fund reserve £3000

Details of any funds materially in deficit

All of our expenditure was significantly less in 2020 when compared to 2019, however due to the cancelled conference in May 2020 our overall profit was £235 less than 2019.

The BACME account is not in deficit and continues to generate a small but healthy profit.

[BACME Financial Report March 2020](#)

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

BACME hold no material assets in terms of buildings, IT or any type of equipment. BACME does not pay any person on the board of trustees. Nor is it permitted to. All positions held are delivered on a voluntary basis or as a very small proportion of their professional roles. Our 2020 conference had to be cancelled due to COVID -19 and the £9195 conference fees received have either been refunded or held over for attendance at BACME's future conference. BAME's main income is from membership fees. And main expense is maintenance and development of BAME's website provided by Circle. It is hoped that BACME's May 2021 virtual conference will generate a profit of up to £5000 for reinvestment in BACME activities for the relief of sickness for public benefit. This includes investment in its website. BACME have not increased membership fees for several years and an increase of £5 on our membership fees would increase income by around £800 per year. Increasing BACME membership by 20% would increase income at current rates by around £800 per year. It is hoped that this will be achieved by raising the profile of BACME and communicating all the benefits that BACME has to offer. The more professionals in the field of CFS/ME BACME can reach, the better able we will be to deliver BACME purpose of "the relief of sickness" for patients with CFS/ME. Reducing website costs could have significant benefits, not only financially but also in terms of improved functionality and accessibility for members. However this would require significant upfront investment and would need to be on a spend to save basis. Now that BACME has achieved CIO status, it would seem an opportune

time to consider BACME rebranding and marketing and it would be great to see this alongside a new website.
BACME is led and delivered by professionals in the field of CFS/ME on a voluntary basis with some executive trustees having a few hours a week of their professional roles dedicated to this. Considering any income generation initiatives for the benefit of BACME members and the delivery of its purpose, needs to be considered carefully in the light of this. Thought will need to be given with regards to paying for services such as webinar speakers and administrative support. Members' views would be very welcome on this dialogue as we move forward as an organisation.

Section F Other optional information

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Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)		
Position (eg Secretary, Chair, etc)		
Date		